Medicine, Health Care and Philosophy
https://doi.org/10.1007/s11019-018-9858-6

SCIENTIFIC CONTRIBUTION

Learning from deep brain stimulation: the fallacy of techno-solutionism and the need for 'regimes of care'

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Abstract
Deep brain stimulation (DBS) is an effective treatment for the debilitating motor symptoms of Parkinson's disease and other neurological disorders. However, clinicians and commentators have noted that DBS recipients have not necessarily experienced the improvements in quality of life that would be expected, due in large part to what have been described as the 'psychosocial' impacts of DBS. The premise of this paper is that, in order to realise the full potential of DBS and similar interventions, clinical services need to be arranged in such a way that these psychosocial dimensions are recognised and managed. Our starting point is that the psychosocial effects of DBS 'in the field' present us with analytically-useful disruptions: they disturb and foreground deeply held assumptions relating to the individual, health and its treatment, and which in a crude form manifest as the myth of technological solutionism within health care. Drawing on scholarship in medical sociology and science and technology studies (STS), we argue that DBS brings to the fore the relational dimensions of personhood, and demonstrates the emotional and social turmoil that can result if the relational dimensions of personhood are ignored by clinical services. In light of this, we argue that DBS should be implemented within a *regime of care*. Drawing on ethnographic research of a paediatric DBS clinical service, we provide an example of a regime of care, and conclude by reflecting on what other DBS services might learn from this paediatric service.

Keywords Science and technology studies (STS) · Cyborgs · Relationality · Chronic illness · Parkinson's disease · Psychosocial

Introduction

Deep brain stimulation (DBS) is now widely considered to be an important clinically effective treatment for Parkinson's (Okun 2014). DBS involves using a cardiac pacemaker-like device to deliver constant electrical stimulation to areas deep within the basal ganglia region of the brain. While this does not halt the progression of the underlying disease, it can substantially reduce motor symptoms such as tremor and rigidity. For many recipients, this can result in a dramatic improvement in their day-to-day function. There is now considerable evidence that this demonstrated clinical benefit off-sets the relatively high-upfront cost of DBS, and it has, then, been deemed as cost-effective (Pietzsch et al. 2016; Eggington et al. 2014). DBS services have therefore been established in many OECD countries, and well-over 150,000 people with Parkinson's have received DBS worldwide (Medtronic 2017b). For these reasons, DBS is the most important advancement in treatment of Parkinson's treatment since the introduction of levodopa-based treatments in the late 1960s, and perhaps one of the most significant therapeutic developments to have emerged out of the neurosciences in the last 30 years or so. Clinicians and device manufacturers have been encouraged by the success of DBS for Parkinson's to explore other therapeutic applications for the DBS technology. It has since been approved in the EU and elsewhere (and partially approved in the US) for the treatment of dystonia (a movement disorder characterised by sustained muscular contraction), it has been approved for the

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Published online: 01 August 2018

treatment of obsessive compulsive disorder, and it is being trialled for the treatment of chronic depression (Okun 2014).

Despite its obvious success at reducing debilitating symptoms of movement disorders, the implementation of DBS as a routine intervention within clinical services has been characterised by tensions and challenges. For some time now, clinicians have noted that some DBS recipients have not experienced the improvement in quality of life that would be expected given the marked reduction in the severity of their motor symptom (Schüpbach et al. 2006; Agid et al. 2006). This divergence has been attributed to the psychological and social dimensions of their illness and the DBS treatment. In some cases, DBS recipients are disappointed with what they feel is still an insufficient improvement in their condition, while in others, recipients' significant improvement after years of debilitation can upset spousal relations and family dynamics (Gisquet 2008). More dramatically, in approximately 5% of recipients, DBS has induced striking changes in mood and behaviour, such as mania, impulsivity, and hyper-sexuality, resulting in severe emotional strain on the recipient and family members (Temel et al. 2006).

These so-called 'psychosocial effects' are not unique to DBS—similar issues are associated with other neurological interventions including drug-based levodopa treatments for Parkinson's (Beaulieu-Boire and Lang 2015) and ablative therapies for epilepsy (Jecker and Ko 2017). In this regard, DBS represents an illustrative case study for exploring some of the social and ethical dimensions of the intersection of chronic neurological illness and medical treatments. Additionally, however, DBS is also a pertinent case study because, as a high cost intervention surrounded by considerable promissory excitement, it is representative of a commonly envisaged future of technologically advanced healthcare (Gardner 2013). The premise of this paper, then, is that DBS offers important lessons about how other contemporary and future 'high-tech' interventions for chronic illnesses might best be implemented in routine care. The foci of this paper are the psychosocial effects experienced by some DBS recipients, and particularly the ways in which these effects are delineated and managed in clinical settings. Our starting point here is that these effects and their management 'in the field' present us with *analytically-useful disruptions*. We see them, in other words, as disturbing and bringing to the fore deeply held assumptions relating to the individual, health and its treatment, and which in a crude form, as we will illustrate, manifest as the myth of technological solutionism. More specifically, in this paper, we illustrate how the potential psychosocial effects of DBS disrupt a key assumption that underpins legal and ethical instruments in healthcare and indeed prevalent, common-sense thinking about health: that people are autonomous, atomistic and strategically rational individuals. Drawing on scholarship in medical sociology and Science and Technology Studies (STS), we argue that DBS brings to the fore the relational dimensions of personhood, and demonstrates the emotional and social turmoil that can result if the relational dimensions of personhood are ignored by clinical services. In light of this, we argue that DBS and similar biomedical interventions for chronic care should be implemented within what we define as a *regime of care*.

We begin by providing a brief description of the ideology of technological solutionism that underpins much of the optimism and hype that surrounds biomedical technologies. Part of the appeal of technological solutionism, we argue, is that it broadly aligns with the now common portrayal of people as being autonomous, atomistic healthcare consumers engaged in rational cost-versus-benefit problem solving. We then draw on existing reports of the psychosocial effects experienced by some DBS recipients to illustrate its disruptive impact. Our approach here is indebted to scholarship criticising the 'tyranny of autonomy' in Western medicine (e.g. Prainsack 2017; Foster 2009), and in particular, to existing work in STS on human–machine hybrids, or 'cyborgs' in healthcare (Oudshoorn 2015; Haddow et al. 2015). There is an ethical utility, we suggest, in conceptualising DBS recipients as cyborgs which are constituted by relational networks of care. These networks disrupt conventional understandings of autonomy and challenge the ideals underpinning technological solutionism. By conceptualising DBS recipients in this way, we are obliged to encourage service models that actively foster the relations of care that are needed to sustain cyborgs. Such service models, in other words, are required to ensure that the maximum benefit—as perceived by recipients and families—can be derived from high-cost interventions such as DBS. It is in this vein that we then advocate a 'regime of care'. Drawing on Annemarie Mol's (2008) influential reflections on care practices, we define a regime of care as: *a set of practices which aim to foster the social and technological relations necessary for a meaningful quality of life as perceived by the patient*. There are some clinical services that do indeed appear approximate a regime of care and which can, therefore, serve as a useful exemplar for services elsewhere. Hence, drawing on ethnographic research conducted by the first author with a paediatric team providing DBS (which is published in Gardner 2017b), we provide examples of the types of practices that constitute a regime of care. We conclude by reflecting on what other DBS services, and services implanting other 'disruptive' treatments for chronic illness, might learn from this paediatric team.

Technological solutionism and the autonomous, atomistic individual

Technological solutionism is an ideology in which social phenomena are delineated as discrete problems that can be ameliorated, or as discrete processes that can be optimised, with an appropriately designed technological intervention. As Morozov has described it, it is:

> [The] recasting [of] complex social situations either as neatly defined problems with definite, computable solutions or as transparent and self-evident processes that can be easily optimised – if only the right [technologies] are in place (Morozov 2013).

We suggest that the ideology of technological solutionism, in other words, is underpinned by four principle ideas. First, it is animated by what Li has referred to as the 'will to improve' (Li 2007); the presumption that the current state of affairs is deficient, and that change therefore needed to, for example, create greater economic wealth. Change is thus assumed to be inherently good. Second, as Morozov's definition above makes clear, technological solutionism is underpinned by the idea that social phenomena can be bracketed as discrete process with intelligible problematics. It also presumes that technologies themselves can be bracketed as discrete interventions with predictable (and desirable) effects. Fourth, technological solutionism therefore also assumes that undesirable and desirable social processes will be clearly delineable and distinguishable; it assumes, in other words, that the advantageous consequences of a technological intervention will be easily apparent to involved stakeholders.

The ideology of technological solutionism and the notion of a 'technological fix' has become ubiquitous in many OECD countries. In its most crude form, technological solutionism is especially apparent in much of the rhetoric surrounding digital technologies and the championing of digital hubs à la Silicon Valley. The so-called 'digital revolution', for example, is described as having the capacity to produce a range of interconnected technological platforms for optimising everyday tasks (such as rubbish collection, driving, hailing a taxi), thus bringing about a more efficient, 'on-demand economy' (Schwab 2016). Indeed, more generally, the ideas underpinning technological solutionism align with the valorisation of innovation that characterises current industrial strategies within OECD countries (de Saille and Medvecky 2016). Biomedical innovation in particular has been identified by countries such as the UK, Australia, Japan, and various US states as a valuable source of potential 'health and wealth'. Fields such as the neurosciences, regenerative medicine and precision medicine, for example, have been actively promoted by governments for their potential to bring about new technological solutions for illnesses for which there is currently unmet clinical need (Gardner et al. 2017; Samuel and Farsides 2017). This faith in technology is a defining feature of the heavily technology-mediated western medical practice more generally (Gardner 2014). Widely championed 'innovation' in healthcare tends to be equated with the development and introduction of new technologies, whether they be high-cost surgical robots or stem-cell therapies, or 'mundane' information and communication technologies, such as electronic patient records or telemedicine technologies.

The prevalence of technological solutionism, we argue, can be partly explained by its resonance with the widely-held assumption in Western medicine that people are autonomous, atomistic individuals. In particular, the technological solutionist ideals that social phenomena can be bracketed as discrete processes with intelligible problematics, and that technologies can also bracketed as discrete interventions with predictable effects, aligns with the Western notion that individuals are themselves autonomous, bounded entities that rationally and individually appraise 'cost versus benefits' when seeking healthcare. Both technological solutionism, and the Western notion of the autonomous individual reflect the ontological stance that the world is composed of discrete entities with inherent attributes which engage in intelligible cause-and-effect interactions. Western political philosophy has reified this ontological stance (Barad 2007). Thinkers such as Kant, Locke, and Hobbes, as Prainsack (2017) notes, equated agency and dignity with the individual's rational self-awareness and their capacity to therefore express free will, conceptualised as being able to act independently from others. This perspective, with its strong foothold in disciplines such as economics, law, and indeed bioethics, has had a strong influence throughout Western societies and, as Prainsack notes, frames human practice as being measurable and predictable. Hence, it underpins much of the legal and ethical governance mechanisms and instruments in healthcare, particularly the notion of informed consent (Prainsack 2017). While there are diverse understandings of what constitutes 'informed consent', in general it assumes that a decision is to proceed with, say a technological intervention, is made by one person, based on rational analysis of likely effects.

This conception of the individual, and indeed the notion of informed consent, have been subject to sustained criticism from the social sciences and humanities (e.g. Taylor 1992; Fox and Swazey 2008; Strathern 1988; Baylis 2011; Mackenzie and Stoljar 2000), and particularly among feminist theorists influenced by post-structuralist thought (e.g. Butler 1990; Barad 2007). This work has championed an alternative ontological stance, in which people are conceptualised as the emergent (and ongoing) products of a network of relations. DBS, as we will argue, brings such relations to the fore, and in doing so, it also demonstrates the fallacy of the key underpinning ideas of technological solutionism.

This, in turn, has ethical implications: it necessitates that we deploy DBS within a regime of care that is attentive to subject-forming relations. First, however, we illustrate how technological solutionism has characterised much of the public-facing discourse surrounding DBS.

Technological solutionism and DBS

Over the last two decades, large neuroscience research projects and neuroscience findings have attracted significant public interest, and neuro-technologies such as DBS have frequently been the subject of news media coverage (Racine et al. 2010). While frontline clinicians may be well-aware of their complexities and limitations, much of the public facing discourse on neurotechnologies, such as news media coverage of DBS, tends to perpetuate the ideals of technological solutionism. Content and thematic analysis of news media have found that DBS is portrayed in a highly optimistic light as a technologically advanced solution for the debilitating symptoms of neurological conditions (Racine et al. 2007, 2010; Gilbert and Ovadia 2011). News articles tend to construct a narrative of DBS as a miraculous intervention for conditions such as Parkinson's by focusing on those individual cases in which the recipient has experienced a dramatic improvement in their movement disorder symptoms, while the more modest gains experienced by the majority of recipients and psychosocial effects by some are ignored (Bell et al. 2009). And, as Racine and colleagues highlight in relation to the articles in their study, when ethical issues are noted, they tend to be equated with informed consent and respect for autonomy, while the reliability of the technology, discrimination and stigma associated with the treatment, and the wider policy dimension of the technology (that is, issues which may complicate the ideals of technological-solutionism) were not mentioned (Racine et al. 2007). Such coverage, then, highlights the novelty of the DBS technique and its significant clinical potential, and while it does not explicitly state that DBS is a permanent solution for Parkinson's, it does give the impression that it is a relatively straightforward biomedical intervention with therapeutic effects that are unquestionably desirable.

Official online information for potential DBS recipients is more cautious in its public presentation of the technology, but it too tends to provide an optimistic picture of DBS that elides the complexity of its effects. Such material is provided by DBS device manufacturers such as Medtronic and Boston Scientific, and keeping in-line with relevant regulatory requirements, promotional material on DBS is carefully phrased to highlight that a positive therapeutic outcome is not certain, that the treatment is not a cure, and that it won't return the recipient to their pre-Parkinson's state. Nevertheless, DBS is framed as an intervention that can significantly enhance the autonomy of recipients, and autonomy is framed in terms of control; it is described as an intervention that, for example, will enable you to 'take control of your Parkinson's symptoms' provide 'additional hours of good movement control each day', and as a therapy that 'fits your daily lifestyle' (Medtronic 2017c). Webpage text is also interspersed with more exalting excerpts from patient testimonies, such as: "DBS… gives you a new life. It makes things possible" (Medtronic 2017a). Webpages also feature imbedded YouTube clips of patients, including positive testimonies and dramatic 'before & after' DBS footage (Medtronic 2017a; Boston Scientific 2017). In this way, the composition of online sites can perpetuate an impression of DBS as a relatively uncomplicated biomedical intervention for debilitating Parkinson's symptoms.

Bell et al. (2009) note that the overall optimistic portrayals of DBS in public-facing discourse can propagate unrealistic expectations among potential DBS recipients (2009). The actual influence of such material on publics' understandings has no doubt been variable, but our own research has illustrated that, at least in one context, some potential DBS recipients and their families appear to have adopted a view of DBS that aligns with technological solutionism—at least according to their clinicians. Here, a paediatric neurologist explains the impact of news media coverage of DBS on some families attending the paediatric DBS service for the treatment of dystonia:

> The problem is the press reports the case studies that do well, so there can be a perception [among our families] that DBS will get my child to walk. Because that's what you read about in the press… And that's a worrying thing for us… managing the expectations - that can become very difficult. (Interview, cited in Gardner 2017b, p. 146)

This quote illustrates the tensions that result from the divergence between the portrayals of DBS in public facing literature which evoke the notion of a 'technological fix', and the actual, complex impact of DBS on the lives of patients and their families. In the following section, we explore this complex impact in more detail, drawing on social science scholarship on 'everyday cyborgs'. Further on, we illustrate that some clinical teams (such as that of the participant quoted here) have institutionalised practices aimed at identifying and managing the complex impact of DBS on recipients and families. These practices, we argue, foreground the relationality of personhood, and serve as an important illustration of what we define as a 'regime of care'.

Disruptions: DBS cyborgs, relationality, and care

Much of the sociology, STS and feminist scholarship on biomedicine and healthcare is premised on an implicit (if not explicit) scepticism of technological solutionism. Conventionally, these disciplines have been concerned with interrogating promissory biomedical discourses surrounding technological innovation, with interrogating the often otherwise obscured political and ethical dimensions of biomedical technology, or with foregrounding the role of biomedical technology in subject-forming relations (Timmermans and Berg 2003). Such work has demonstrated the fallacy of the principle ideas that underpin technological solutionism: what constitutes 'a medical problem' that requires 'improvement' is far from straightforward and might be hotly contested by different communities (Blume 2009). Technologies are socially embedded and cannot be bracketed as discrete interventions (Faulkner 2008), and the supposed advantageous consequences of a technological intervention can be muddied by unanticipated ethical challenges (Williams 2006). The work in this vein that is particularly relevant to this paper, however, is that which explores machine-human hybrids, or cyborgs as Haraway (1991/2006) influentially defined them, and in particular what have been referred to as 'everyday cyborgs' (Oudshoorn 2015; Haddow et al. 2015; Blume 2009). In Haraway's foundational reflections, the cyborg represents a positive metaphor for reconceptualising agency by challenging the conventional, widely-held dualisms such as technology/nature, and male/female, that underpin Western metaphysics. Haraway imagines a cyborg that recognises the liberatory potential of being hybrid: in a manner akin to what Deleuze and Guattari (1977) refer to as 'lines of flight', the cyborg traverses traditional binaries and is able to open-up, experience, and move between alternative subject-positions. Haraway's reflections are in a sense techno-optimist, but for her the Cyborg is contrary to the ideals that underlie techno-solutionism: the social and technical are inextricably entwined, and while socio-technical phenomena that facilitate subject-position fluidity are more desirable than those that don't, social phenomena cannot simply be delineated as well-bounded 'problems' requiring solutions. In conceptualising the cyborg and indeed agency in as being deeply relational, Haraway also presents an alternative ontological stance to that which underpins the autonomous, atomistic individual.

Haraway's reflections on the dualism-disrupting and category-antagonising cyborg have provided an analytical springboard for a vast range of scholarship, including a small number of empirical studies of 'everyday cyborgs'—people with (or people considering) implantable medical devices. These studies, which include people with cardiac pacemakers and implantable cardioverter defibrillators (Oudshoorn 2015) and men considering the possibility of implantable prostate tumour biosensors (Haddow et al. 2015), explore the impact of the device on embodiment, agency, and relations of care. These authors note the messages of autonomy that surround such devices: the recipients are framed as passive users of a technology which is pre-programmed and implanted within them, and the devices are championed as enabling the recipient to have greater autonomy and control over their day-to-day life. Yet the actual experiences of these cyborgs complicates this framing of autonomy. First, recipients and potential recipients expressed feelings of anxiousness and precariousness, due to their perception (and indeed their first-hand experience) that such devices were fallible (Haddow et al. 2015; Oudshoorn 2015). Second, for such devices to work correctly, users are required to be tethered to specialist clinical teams, and hence, their autonomy was depended on a network of relations of care. Some recipients lamented this dependency. And third as Oudshoorn notes, these networks of care relations also included the user's own engagement with the device and their body. The success of the device depends on users becoming attuned and responsive to new bodily sensations that might, for example, indicate a fault with the technology. Being an everyday cyborg, then, requires specific embodied sensitivities and the active sustaining of networks composed of a complex interplay between human and material (e.g. bodily, technological) agents (Oudshoorn 2015).

The networks of relations which characterise everyday cyborgs, then, disrupt conventional distinctions between autonomy/dependence, and social/material (that is, social/bodily, social/technological). In this way, they demonstrate the fallacy of the key ideas that underpin technological solutionism. Social phenomena or technological interventions cannot be cleanly bracketed, or a technological intervention may have transformative effects (such as prompting new bodily awareness) that were not predicted and that cannot easily be delineated as either desirable or undesirable. DBS recipients are also important examples of everyday cyborgs. Despite the undoubtable clinical success of DBS in reducing the motor symptoms of movement disorders, it can have a complex impact on recipients and families, characterised by what are often described by commentators as 'psychosocial effects' (Bell et al. 2011). Here, we provide a summary of the impact of DBS, which we argue bring to the fore the relationality of personhood and challenge technological solutionism.

A consequence of DBS is that recipients may become reliant on specialist clinicians. Once the DBS system has been implanted, the stimulation parameters require adjustment to achieve a maximum therapeutic effect and in some cases, to ameliorate undesirable effects such as speech disturbances (Ostrem and Starr 2008). The optimal stimulation parameters will vary between individuals and it may take many weeks for them to be identified. Additionally, parameters may be incrementally adjusted over time as the underlying disease progresses. Specially trained clinicians are required to make the adjustments, and recipients, then, are tethered to specialist services which are generally located at large hospitals in major metropolitan centres. Other concerns also create a reliance on specialist services. Hardware failures, infections, and depleted batteries all necessitate the attention of a DBS team that includes a neurosurgeon. While such events are rare, Gisquet (2008) has noted that some DBS recipients experience anxiety and fear over a perceived fragility of the DBS hardware. The underlying progression of Parkinson's necessitates greater engagement with clinicians, but the DBS system, Gisquet noted, heightened their sense of dependency on specialist DBS clinicians; a dependency that they lamented, and which was also in contrast to their experience of drug-based treatments for Parkinson's.[1] Gisquet identifies an apparent contradiction: DBS enhances autonomy by improving the recipient's motor systems, but it can also amplify their sense of dependency on medical professionals.

This is, of course, only contradictory if we assume a technological solutionist stance, particularly the underlying idea that technologies are well-bounded, discrete interventions. We however read this as a conspicuous confirmation of the STS tenet: that the utility of technologies is product of their emersion within a wider network of actors (Faulkner 2008). Timmermans and Berg (2003) have argued that the agency of a medical technology (e.g. its capacity to enhance users sense of independence) is the product of interactions involving an assemblage of distributed actors that may include designers, users, maintainers and other technological systems. Hence, as with other 'everyday cyborgs', DBS recipients become closely embedded within such an assemblage, an assemblage that includes highly-trained professionals and that, for a few recipients, is experienced as an oppressive dependency.

The psychosocial effects experienced by some DBS recipients also disrupt the ideals underlying technological solutionism. These effects were first described in some detail by French DBS services (Agid et al. 2006; Schüpbach et al. 2006), and have since been summarised in more detail by Bell et al. (2011). French clinicians noted that a significant proportion of their cohort were have difficulties adjusting to social life after the DBS system had been implanted, despite a reduction in their motor systems. They note, for example, that many recipients perceived that their financial situation, social life, and relations with family had worsened, while over half felt that their marital life and professional life had worsened. One important effect of DBS described by Schüpbach and colleagues (2006) is its influence on a recipient's 'passion for life' and drive, or what they define as vitality. What interest us here is that according to the accounts provided by Schüpbach and colleagues, DBS may be associated with a loss of vitality, or it may enhance vitality. In one case, for example, a recipient who had a major improvement in her motor symptoms also "had a loss of inspiration and a taste for her work… Her family no longer interested her" (Schüpbach et al. 2006). While in another case:

> The patient regained confidence in himself and aspired to more autonomy: "I want to recover my social standing and establish new relationships outside my couple. During all these years of illness, I was asleep. Now I am stimulated, stimulated to lead a different life." (Schüpbach et al. 2006)

This potential of DBS to have either impact does of course challenge the technological solutionist ideal that technological interventions have predictable effects. However, this example also illustrates that the whether such effects constitute an 'improvement' or 'worsening' may be disputed among the recipient and their family, and indeed is deeply dependant on the recipient's circumstances. In their outline of the case described in the extract immediately above, Schüpbach and colleagues add that the DBS recipient's wife was deeply troubled by her husband's behaviour; "Before… we were a perfect couple. Now, he wants to live the life of a young man…". They note that a "grave conflict was caused by the newly regained autonomy of the patient and his wife's loss of status as caregiver." (Schüpbach et al. 2006). DBS, in effect, substantially altered the relational, status-forming dynamic between the husband and wife; for the wife, this has been a distressing experience.

As Bell et al. (2011) note, the effects of DBS for some recipients can be so profound that they may be described as constituting a change personality. DBS can induce changes in mood behaviour that family members will describe as being 'out of character'. In this example from an interview undertaken by one of the authors (NW), a spouse provides a description of her husband:

> He was always friendly and warm, but [after the DBS system was implanted], I noticed the coldness, the remoteness; he'd always been easy-going and then he started to get very short tempered, impatient. I couldn't reason with him… And then all the bizarre behaviour started. Like going to auctions and buying things. (Interview)

Indeed, as with other neurological interventions (including drug-based treatments for Parkinson's), DBS can induce impulsive behaviours such as gambling and hyper-sexuality. Here we see the unintended transformative impact of DBS:

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[1] Drug regimens can be altered by neurologists or general practitioners who are more widely available, and as other studies have illustrated (Baszanger 1989), patients can also gain a sense of independence by juggling their medications.

becoming a DBS cyborg can entail the development of new attunements and proclivities, the dulling of previously-held ones, and hence the acquirement of a new orientation to the world. As the above extract suggests, such transformations can in some cases be deeply distressing for family members.

The experience of DBS cyborgs deeply challenges the ideals underlying technological solutionism, particularly the presumption that social phenomena (i.e. an individual's chronic illness) can be bracketed as discrete processes with intelligible problematics. In living with serious chronic illness, people become immersed in relations of care with roles and responsibilities that shape identity and status—the importance and undesirability or desirability of these may only become apparent to those involved once these relations of care have been disrupted with interventions such DBS.

The disruptive psychosocial effects of DBS have become the focus of bioethical discussion on the experience of disease, its treatment, and their relationship to identity and personhood. For some authors, it is the psychological impact of DBS on the individual recipient that warrants ethical discussion. (Schermer 2011; Merkel 2007). Glannon argues, for example, that stimulating the brain can disrupt identity and sense-of-self by undermining the "integrity and continuity of psychological properties that constitute the self" (Glannon 2009). As Baylis (2011) has noted, however, framing the problem in this way tends to elide the relationality of personhood: identity and personhood are conceptualised as being the reflexive expression of an individual's core traits and inclinations. Such a perspective, then, broadly echoes the widely-held assumption that people are autonomous, atomistic individuals, and it has the effect of obscuring the impact of DBS on family members. Other commentators have seen the disruptions of DBS as an opportunity to argue for other, more 'holistic' conceptualisations of personhood and identity (Keyser and Nagel 2014; Mecacci and Haselager 2014; Baylis 2011). For Baylis, DBS must be viewed through the lenses of a perspective in which personality is viewed as emerging from autobiographical narrative and social interactions, both of which are shaped by cultural and political context. Mecacci and Haselager have argued in favour of a 'systems perspective' in which a person is composed of innumerable interconnected feedback loops that traverse biophysiological and societal domains. It would not be unexpected, then, that DBS would have effects that spill-over from one domain into another. The authors suggest that such a view has clinical utility: encouraging potential DBS recipients and their clinicians to adopt a holistic perspective can better sensitise them to—and prepare them for—the psychosocial effects of DBS. Our endeavour here is very much in accordance with these authors: in reframing DBS recipients as everyday cyborgs, we have sought to foreground the relational dimensions of chronic neurological illness and its treatment and highlight the fallacy of technological solutionist ideals.[2] This, we will now argue, has important implications for the provision of DBS.

Towards a regime of care

Bell and colleagues (Bell et al. 2009) argue that the potential psychosocial effects of DBS necessitate specific clinical arrangements. Ideally, they suggest, DBS should be implemented by multidisciplinary clinical teams that include neuropsychiatrists, psychiatrists and advanced care nurses, in addition to neurologists and neurosurgeons. Such teams will be well-suited to screening DBS candidates to ensure that only those patients who are "physically, cognitively and emotionally capable of tolerating the surgery and participating in their own post-operative care" are selected to proceed with the intervention (Bell et al. 2009). Here, we build on Bell and colleagues suggestions and provide a more detailed description of actual clinical practices that have been developed to ensure that DBS is implemented responsibility.

These practices have been developed within a clinical team providing DBS to children and young people with a movement disorder called dystonia.[3] Dystonia is characterised by uncontrolled muscular contraction and, like the symptoms of Parkinson's, in some cases can be dramatically reduced with DBS. Similarly, some DBS recipients with dystonia have reported difficulties adjusting to their newfound sense of autonomy, and have expressed a desire for greater guidance and support (Gun-Marie et al. 2011). Mood swings have also been identified among this cohort (although the cause of these is uncertain, and they appear to be far less dramatic than those experienced by some Parkinson's DBS recipients (Gun-Marie et al. 2011)). And as with DBS for Parkinson's, news media coverage of DBS for dystonia has portrayed it in a highly optimistic 'technological solutionist' light that encourages unrealistic expectations among patients and families (Gardner et al. 2015). There are, then, similar challenges in treating both movement disorders with DBS. In response to such challenges, the clinical team that serves as an example here—which we will refer to as the Paediatric Motor Disorder Service (PMDS)—has developed novel clinical practices for managing the expectations of patients and preparing them for everyday-life with DBS. In effect, these practices attempt to foster the social relations that are needed to care for DBS recipients, and in doing this, reflect a deep awareness among the PMDS of the network of relations that are needed to sustain DBS cyborgs. This is of course a reflection of its paediatric focus and the common perception that all children are dependent on family or carers (the clinical director overseeing the team describes paediatric services as 'treating families, not patients'). Nevertheless, we suggest that the practices of the PMDS team represent an important exemplar for adult DBS services, other services providing major interventions for neurological illnesses, and future services providing high-tech, invasive treatments for chronic illnesses.

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[2] We are aware that using the term 'cyborgs' may exacerbate a sense of abnormality and stigma among DBS recipients. It is important to add, then, that the underlying premise of the STS scholarship described here is that all humans are hybrids of human & 'non-human' components, in so far as our capacity to act 'autonomously' depends on assemblages of technologies and objects, from public utility infrastructures to computer systems. For the most part, these assemblages are mundane, unremarkable, and hence, largely invisible (Latour 1993).

[3] These practices have been captured in the first author's recent ethnographic account of the team (Gardner 2017b)—it is this account which serves as our reference here.

The collective activities of the PMDS team are an example of *a regime of care*. We define a regime of care as a set of practices which aim to foster the social and technological relations necessary for a meaningful quality of life as perceived by the patient. Here, we draw on Mol's (2008) reflections on the logic of care. Effective care, Mol argues, is a collective project that involves a network of people and supportive technologies (including mundane objects and/or high-tech equipment), and also the supported, self-caring individual. We all participate and are subject to care practices in everyday life, but in chronic illness, effective care requires networks that can be difficult to sustain. Designated carers and specialist technological supports may be required, family members may need to adjust to new roles, and the patient themselves needs to actively engage. Effective care networks are emotionally taxing for those involved, and they require constant adjustment so that they are tailored to the specific requirements of the patient. The intricacies of these networks, and the need for them to be responsive and specific, means that they cannot simply be chosen and purchased as consumable services, as is implied in much of the discourse in contemporary healthcare policy promoting 'patient choice' and 'empowerment' (Mol 2008; Cribb 2011). The regime of care that we are championing here aims to foster these networks. It recognises that chronic illness cannot be dissected into clearly delineable problematics requiring technological solutions: living well with chronic illness is a collective, taxing endeavour that has to be continually reviewed by those involved, and it is an endeavour in which unpleasant surprises are not uncommon.

The PMDS is a multidisciplinary team that includes that includes two neurologists, a specialist nurse, a team administrator and several therapists including physiotherapists, an occupational therapist and a speech and language therapists. Within the PMDS, DBS is perceived by team members not as a technological solution, but as one vital component of a therapeutic regime—what we define as a regime of care. As a member of the team states, "DBS unlocks the dystonia so that therapists can get in and give you the functional recovery" (interview, cited in Gardner 2017b, p. 89). The therapists play an important role in selecting appropriate DBS candidates, preparing families for DBS, and working closely with families in an attempt to ensure DBS has an optimal impact on quality of life. To do this, the team has had to devise specific practices that can be routinely implemented with all DBS candidates and families—here we focus on two of these practices, both of which serve as useful illustrations of a regime of care.

The most relevant practice here is the goal setting session (see Gardner 2017b for a more comprehensive account). Goal setting sessions involve the child, their supporting family members (usually parents), an occupational therapist, a physiotherapist, and often a psychologist. They take place after the child has undergone a range of pre-surgical assessments and at least several weeks before the surgical implantation of the DBS system. The aim of the session is to develop a list of specific, realistic goals for families once the DBS is implanted. During the session, the child and their supporting family members are asked to identify five domestic and recreational tasks, such as self-feeding, self-dressing, hygiene-related activities, or using computers, which they would ideally like improve. Drawing on the pre-surgical assessments, the therapists then provide a tentative estimation of how the child's ability to perform each activity will likely improve with DBS, and what other social supports might be necessary to achieve this. In the process, children and families are encouraged to be explicit about their expectations and their hopes, and team members are compelled to provide their predictions using frames of reference (such as the child's ability to self-dress) that are accessible to families. During the goal setting session then, hopes, expectations and the impact of DBS on day-to-day life are discussed in detail. Inevitably, some of the social dimensions of living with chronic illness, and the envisaged impact of DBS on these social dimensions—such as its impact on the care roles of family members—are brought to the fore. The session also provides the team with an opportunity to convey to families that DBS might entail changes in the child's behaviour, and it prompts families to imagine how these might best be managed. Overall, then, the team works hard with families to illustrate that DBS is *not* some sort of technological fix: throughout the session, participants are continually envisaging what networks of care will be required to maximise the benefit of DBS on day-to-day life.

The second practice that we focus on here is the team's deployment of a particular assessment tool, the Assessment of Motor and Process Skills. The Assessment of Motor and Process Skills (AMPS) is championed in in occupational therapy as a being 'patient-centred', and the team has adopted the tool into their regime of pre- and post-surgical assessments (Gardner 2017a). The team believes that the

AMPS captures clinical improvements that are meaningful to families; improvements that are not captured with widely used impairment based measures. To conduct the assessment, the child attempts to perform particular task of daily living that they and their family have identified as important to them—often the same tasks that later become the subject of the goal setting session. The therapists create a mock domestic space within the hospital in which the task is performed, and the child's attempt is video recorded so that their performance can subsequently be analysed and graded. In effect, then, the tool measures the impact of DBS according to outcomes that are important to families, and more generally, it helps ensure that care activities can be orientated towards the achievement of these outcomes.

Both the goal setting session and the AMPS are an important part of the PMDS' regime of care. They help the team to identify and foster the social and technological relations that are necessary for attaining a meaningful quality of life, as perceived by the patient and the family. In doing this, they also foreground the relational dimensions of chronic illness and in particular the networks of care that are needed to sustain a DBS cyborg. There are other features of the PMDS that are also worth mentioning here. The team produces a comprehensive multidisciplinary team report with tailored guidance on how to meet the specific care needs of the child and the family, which can be passed on to social care workers in the community. The team's administrator provides an ongoing point of contact for all families who wish to contact team members and, because families spend quite some time with the PMDS (assessments can take 2 days), team members feel that they are able to establish a rapport and sense of trust with families.

Lessons from the PMDS

The PMDS is the product of a specific institutional context. It reflects a commitment to focusing on families that is common to paediatric services in the UK. Because it is situated in the UK's National Health Service, it also benefits from a commissioning arrangement that provides additional financial support to paediatric services. This has meant that the team can provide comprehensive service with several therapists and a team administrator that would not be financially feasible in adult services. Nevertheless, it represents one important example of how DBS can be implemented within a regime of care. From it, we can derive guidance on what a regime of care might look like in other contexts in which the success of a biomedical intervention depends on care networks that can be difficult to sustain. Such interventions might include the implantation of biomedical devices (such as cardioverter defibrillators or intrathecal baclofen pumps) that create fragile cyborgs, or surgical interventions (such as ablative therapies for epilepsy) that, like DBS, can have complex psycho-social effects.

Most significantly, the example of the PMDS demonstrates the importance of a multidisciplinary approach to such treatments. Multidisciplinary approaches which include neuropsychiatrist and psychiatrists have, as noted above, been recommended by other commentators (Bell et al. 2009), but what the PMDS demonstrates is the value provided by allied health disciplines, particularly occupational therapy. Occupational therapists have positioned themselves as a 'patient-centred' discipline that focuses on patients' capacity to engage in domestic and social activities. Naturally, then, occupational therapists are sensitised to the relations of care that are required to help DBS recipients achieve a meaningful quality of life. Tools from occupational therapy such as the AMPS illustrate that a recipient's capacity to engage in domestic tasks can be captured and used to assess the effectiveness of DBS and similar interventions. We suggest that such tools provide an important alternative to tools like the Unified Parkinson's Disease Rating Scale that focus on the neurological impairment of the individual DBS recipient.

Another important dimension of the PMDS is the degree to which supporting family members are included in PMDS activities. Family members accompany potential DBS recipients throughout their pre-surgical assessments, they are directly asked for their opinions on what would constitute a meaningful improvement from DBS, and they are engaged in conversations about the possible impact of DBS on everyday life. This involvement of family members obviously reflects the young age of patients and the requirement that consent for the procedure be obtained from a legal guardian, but also reflects an understanding of the relational dimensions of chronic care and its treatment. It reflects an understanding, in other words, that DBS is not a technological fix, and that achieving a meaningful gain in quality of life from DBS requires active support and care from family members. Ideally, adult DBS services would also provide an opportunity for carers to actively engage in deliberations, but this would of course need to be balanced with the need to ensure that the patient's decision-making is not unduly influenced by others.

Other services could also learn from the goal setting session of the PMDS. It provides a space for clinicians, the patient, and supporting family members to envisage a likely future with DBS, and thus to envisage how psychosocial effects might be managed should they occur. Adult services might similarly provide a space in which families and clinicians can discuss clear, realistic goals that are specific to the interests and values of the patient. Such discussions would involve identifying the aim of the intervention and in particular the pros and cons of particular effects. For example, in regard to DBS for Parkinson's: is an improvement in gait worth the possible impediment of speech, given the patient's interests? What other care practices and support might help achieve desired aims?

There is no 'one size fits all' model for providing DBS and similar interventions within a regime of care. As with all healthcare services, the exact service model will be shaped by institutional constraints and particularly funding pressures, and it will need to be responsive to local cultural values. Nevertheless, if the full clinical potential of such promising interventions are to be realised, it is necessary that clinicians, patients and families recognise the fallacy of technological solutionism and engage in activities that aim to foster and sustain relations of care. We also suggest that such an approach is especially important given the likely emergence of 'closed-loop' DBS technology in some treatment areas such as epilepsy. These 'intelligent' systems detect neuronal activity that might, for example, indicate an oncoming seizure, potentially enabling recipients to decide on a therapeutic course of action. Foreseeably, then, closed-loop systems can enhance autonomy by helping participants to actively monitor and manage their condition. However, as Gilbert, Obrien and Cook argue, such devices may raise additional challenges (such as an over-reliance on the device), for which prospective patients and their families will need to be carefully informed (Gilbert et al. 2018). We suggest that closed-loop devices will also require a regime of care, although the actual form of such a regime will need to be informed by a greater understanding of the experiences of recipients and their families.

We end here with two contrasting examples of adult services providing DBS for Parkinson's. The first is of a French service that appears to be implementing activities that align with what we have defined as a regime of care. In order to address psychosocial maladjustment issues, clinicians, the DBS recipient and a supporting family member (usually a spouse) participate in a psycho-education programme (Santos et al. 2017). The programme involves eight pre- and post-operation sessions, in which participants are prompted to envisage how they might go about managing psychosocial effects, should the occur. In effect, participants are foregrounding and discussing the relations of care that are needed to 'live well' with DBS. Implementing such activities does of course increase the cost of DBS services, but they are necessary for ensuring that the clinical potential of DBS can be realised. Indeed, a pilot trial of the programme has illustrated that it increases the quality of life outcomes of DBS (Santos et al. 2017).

The provision of DBS within some Australian services provides a stark contrast. In Australia, DBS is provided mostly in private clinics and is funded via private health insurance or publically-funded universal healthcare schemes. Depending on the price mark-up of the clinic, patients themselves may have additional out-of-pocket costs. The exact structure of a DBS service, and the support provided to patients and their families, will therefore differ significantly between providers. Some providers have employed a specialist movement disorder nurse that recipients and caregivers can contact at any time. Some services, however, have been publically criticised for their failure to provide support, which has caused considerable stress to family members (Stevens 2015). These service arrangements might be relatively low cost compared to a more comprehensive approach, but if families are failing to experience a meaningful improvement from DBS, then they may represent an irresponsible deployment of scarce resources. In the absence of a regime of care, the future of interventions such as DBS—and their immense clinical potential—could be threatened.

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